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SOCIAL SUPPORT FOR SIBLINGS OF CHILDREN WITH CANCER

a thesis

by

JOHN STEPHEN MURRAY

submitted in partial fulfillment of the requirements

for the degree of

Master of Science

May 1993

Abstract

Social Support for Siblings of Children With Cancer

John Stephen Murray

This descriptive study investigated nursing
interventions used by Pediatric Oncology Nurses to
provide social support to siblings of children with
cancer. The study was guided by the model described by
House (1981) which posits major categories of social
support variables including emotional, instrumental,
informational, and appraisal support. A sample of 250
pediatric oncology nurses were mailed the Sibling Social
Support Questionnaire (SSSQ), developed by the
researcher, to assess what interventions they use in
clinical practice to provide social support to siblings
of children with cancer. With 134 respondents, the SSSQ
demonstrated high internal consistency with a Cronbach's
alpha of .95.

Results indicated that the two most frequently used
interventions to provide social support to siblings are:
(1) encouraging parents to spend time with their other
children and (2) providing honest responses to questions
asked by siblings.

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Dedication

This work is dedicated to my parents, Joseph and Inez Murray, whose love and support helped my brothers, sisters and I to cope with our family's childhood cancer experience and to my brother, Danny, whose battle with childhood cancer has given me the inspiration to pursue my work in pediatric oncology.

Introduction

The ache in my sister's side would begin a long journey for our family through distress, death and love. We were all on the same road, but miles apart. As her illness became the focal point in our lives, jealousy, anger and confusion jumbled in my mind. I wondered if our family would ever be the same.

I began to feel hatred for my sister. I often thought if I got sick, maybe I too would receive presents and sympathy. My sister stood bathed in the spotlight, and I'd been thrown into the corner. I resented her. I thought everyone was totally insensitive to me. People would always ask me how she was doing, never how I was doing. I was suffering just as much as she was - not physically, but emotionally. I became very tough on the outside, but I was dying on the inside. (An excerpt from an essay written by a sibling of a child with cancer)

The diagnosis of cancer in any family member can be a devastating experience for the entire family. However, when the family member is a child, the experience seems even more traumatic. This announcement disrupts the "natural order" of life where it typically

is the elderly that suffer and die and the young who carry on with the work of life (Rollins, 1990). It should come as no surprise that the news of such a disease, with all of its uncertainty and uneasiness, would be ample cause for crisis in any family system.

With recent advances in medical technology, the diagnosis of childhood cancer has changed from being one of an acute illness to that of a chronic nature (Cohen, 1985). However, despite the brighter outlook for today's children with cancer, they still endure repeated hospitalizations and clinic visits, lengthy courses of rigorous chemotherapy and/or radiation, painful procedures, changes in physical appearance, lack of energy and frequent absences from school. The overwhelming demands of this disease, including the prognosis, are unpredictable elements that cause enormous stress for all family members and must be dealt with on a daily basis (Rollins, 1990).

These demands of cancer on a child and their parents have been studied and understood for many years now. (Binger, Albin, Feurstein, Kushner, Zoger, Mikkelson, 1969, Chesler and Barbarin, 1987 Cobb, 1956, Morrow, Carpenter and Hoagland, 1984). However, very little focus has been placed on one other very important part of the family system - the siblings. In the health

care profession today, there is a growing awareness that the psychosocial needs of siblings of children with cancer are less adequately met than those of other family members.

Throughout the literature on childhood cancer, siblings are often referred to as the "forgotten grievers." According to Chesler and Barbarin (1987), siblings are the most left out and unattended to of all family members during the experience of serious childhood illness. Rollins (1990) points out that it should come as no surprise that siblings are overlooked in the process at the time of diagnosis. The focus of the health care professionals, family and friends is on the ill child and parents. In a study by Tritt & Esses (1988) it was the healthy siblings who were identified as the most unhappy members in one-third of families interviewed who had a chronically ill child. Over one-half of the siblings interviewed believed that the ill child received special treatment. The brothers and sisters of the ill child learn and feel that their needs are secondary to those of the ill child.

Traditionally, the primary emphasis in pediatric nursing has been placed on the parent-child dyad. However, today there is increasing recognition of the powerful influence that siblings have on each other.

Sibling relationships are often characterized by their intensity, complexity, and ambiguity (Trahd, 1986). The span of time these relationships encompass is one of the most critical elements that contributes to this intensity and complexity.

Childhood cancer can have damaging effects on the psychosocial well-being of the healthy sibling, as well as the relationship between the healthy sibling and ill child. Some of these changes are undoubtedly attributed to the enormous demands of the disease while others are a result of the dynamics of the sibling relationship itself (i.e. ages, birth order, child spacing within families, previous relationships). An enormous potential exists for siblings to be an extraordinary source of support, strength and comfort for each other, when confronted with the demands of cancer, because of the very powerful relationship they share (Rollins, 1990). Nurses, and all health care providers, should explore ways to take advantage of this bond and use it in a positive and proactive way to enhance family coping and empower the family system.

One way of improving the psychosocial adaptation of siblings of children with cancer, is through the implementation of social support interventions. There are a number of studies in the literature that address

the importance of social support for reducing the
psychological distress related to the intense stressors
of serious illness such as cancer (Dunkel-Schetter,
1984, Morrow, Carpenter and Hoagland, 1984, and Taylor,
Falke, Shoptaw and Lichtman, 1986). Social support can
be a valuable resource in helping siblings of children
with cancer cope with the many psychosocial demands of
the childhood cancer experience. There is a paucity of
research on the sources of support for families living
with chronic illness (Woods, Yates, Primomo, 1989),
however, research on sources of support for siblings in
particular, is practically nonexistent. More emphasis
on the use of social support in mediating the
maladaptive outcomes of siblings is critical. The types
of social support identified by Dunkel-Schetter (1984)
as being invaluable to patients with cancer (emotional,
informational support) should also be utilized in
working with siblings of children with cancer. In
addition, instrumental and appraisal support should be
considered as moderators of stressors in the childhood
cancer experience as well. In the same article Dunkel-
Schetter points out that it is clear that support from
health care providers is important. As in practice in
adult oncology, every effort should be made by care
providers working in pediatric oncology to

employ these types of supports with family members and siblings in particular.

Purpose of the Current Study

The purpose of this study was to investigate the extent to which Pediatric Oncology Nurses utilize specific nursing interventions in pediatric oncology nursing practice, to help siblings of children with cancer cope with a potentially traumatic experience. The limited research done over the past 30 years has identified many maladaptive outcomes in children who have a sibling with cancer. Included in these studies were recommendations of interventions that may be helpful in reducing the incidence of such outcomes. The major goal of this study is to learn more about the use of these interventions in clinical practice and make recommendations to Pediatric Oncology Nurses that will be instrumental in helping to optimally meet the needs of siblings.

Significance of Study/Relevance to Nursing

The identification of the extent to which nursing interventions are utilized in pediatric oncology nursing practice to minimize the traumatic impact of childhood cancer on healthy siblings, will aid in the evaluation of current practices unique to the pediatric oncology work setting. This information will help nurses to evaluate whether their approach to the care of the pediatric cancer patient includes siblings in the process. This insight into pediatric oncology nursing practice has the potential to result in the adoption of new intervention strategies to facilitate the healthy sibling's emotional adaptation to the childhood cancer experience.

Information about these nursing interventions would be instrumental in the academic setting as well. Faculty will use this knowledge to teach students in undergraduate programs the effects of the childhood cancer experience on healthy siblings. Students will learn that, just as with the child with cancer, a comprehensive approach to sibling intervention is necessary and requires the psychosocial assessment of non-disease as well as disease-related stressors. Ultimately, increased knowledge will result in a decrease in the incidence of maladaptive outcomes and

the enhancement of coping with an adaptive outcome.

Problem Statement

The major research questions for the study are as follows:

(1) What interventions do Pediatric Oncology Nurses utilize in clinical practice to provide social support to siblings of children with cancer?

(2) Which nursing interventions to provide social support are utilized more frequently in clinical practice?

(3) Which nursing interventions to provide social support for siblings of children with cancer are utilized more frequently according to educational degree, years of pediatric nursing experience and practice responsibility?

<u>Definition of Terms</u>

(1) In this study, <u>social support</u> is defined as an
interpersonal transaction to meet the needs for
emotional, instrumental, informational, and/or
appraisal support (House, 1981).

   a. Emotional support - fosters feelings of comfort
and security leading an individual ᴄo feel
loved, respected, understood, and cared for;

   b. Instrumental support - provides direct help or
material aid;

   c. Informational support - provides information or
guidance to help a person better understand and
adjust to changes in his/her life;

   d. Appraisal support - pertains to self evaluation,
acknowledging that one's beliefs and
interpretations of a situation are appropriate.

Each of these types of support have also been classified
into other typologies (Kahn and Antonucci, 1980,
Norbeck, 1985.) However, these four types of support
constitute a minimal set of elements inclusive in other
conceptions of the term.

Social support is operationally defined by the
Sibling Social Support Questionnaire developed by the
investigator. The Sibling Social Support Questionnaire
is a 30 item, Likert scale instrument used to identify

the extent to which Pediatric Oncology Nurses utilize
social support interventions in clinical practice with
siblings of children with cancer. The possible score
range on each item is as follows: Never (1) to Always
(4). The possible score range for the entire instrument
is 30-120.

(2) Nursing interventions are defined as actions
     implemented to provide supportive care to siblings
     of children with cancer.

(3) Pediatric Oncology Nurses are defined as registered
     nurses specializing in pediatric oncology nursing
     for a minimum of 6 months.

(4) Siblings of Children with Cancer are defined as
     children related through birth (blood ties), step
     ties, adoption or through sharing the same
     household.

Chapter 2

Review of the Literature

Most of the research conducted in the area of sibling response to the childhood cancer experience has been done by researchers in the fields of medicine, psychology, and sociology. It was not until the past decade that the nursing profession became involved in research on sibling adaptation to childhood cancer. The following review of the literature clearly demonstrates the paucity of systematic research in this area and the need for nurses to conduct more research that could be implemented in clinical practice to help in preventing, or reducing, maladaptive outcomes in siblings.

The first studies reviewed are three classic retrospective studies. What they reported is evidence that siblings of a child who dies are at increased risk for developing severe psychosocial problems. The earliest research in this area, conducted by Cobb (1956), was initiated to look at the psychological impact of illness and death on the family. A major focus was on the impact of cancer on other children in the family. A convenience sample consisted of parents of children who died of cancer. The author used a retrospective exploratory design with an unstructured interview. Excerpts from the interviews were provided

to report research findings. Major findings as reported by parents, included feelings of loneliness, sadness, and loss of parental availability to siblings. Concluding statements reflected the need to consider the psychological impact of the disease and death of the child on the _entire_ family.

In 1964, Cain, Fast and Erickson studied children's disturbed reactions to the death of a sibling. This retrospective exploratory study was undertaken in an attempt to investigate the range of enduring symptoms and character changes resulting from sibling death reactions. The sample of convenience consisted of 58 children between the ages of 2-1/2 to 14 years who were psychiatric patients being seen in both inpatient and outpatient mental health facilities. Their presenting symptoms in therapy were noted to be in some way related to the death of a sibling. Most of the data was collected from files of materials ranging from outpatient evaluations to years of inpatient treatment. Standardized unstructured interviews were employed with clinical observations. The authors found that the most immediate reactions had a heavy emphasis on guilt, which remained consciously active five years or more after the sibling's death. Reactions to the guilt included depression, withdrawal, accident prone behavior and

constant provocative testing. Ultimately, these behaviors led to poor school performance and feelings of low self worth. Another major recurring theme was that of distorted concepts of illness and death. Present in all the children's responses was a heightened fear of death and fear of contracting the same illness their brother/sister had died from. The authors concluded that further clinical study of the psychopathology of siblings of children who have died would be of immense preventive value.

This information, as in the previous study, would be beneficial in stimulating the development of intervention strategies. Although the sample was a convenience sample, therefore having limited generalizability, several important findings resulted.

Binger, Ablin, Feurstein, Kushner, Zoger and Mikkelsen (1969) reported that, in approximately half of 20 families studied, one or more of the previously well siblings showed significant maladaptive behavioral patterns during the patient's illness that were indicative of coping difficulties. In addition, the problems intensified following the death of the ill sibling. This retrospective study of families who had lost a child to leukemia, was undertaken to help other families cope with the crisis of childhood cancer. The

parents of these families, conveniently sampled, were interviewed by a child psychiatrist regarding the impact of the crisis and its consequences upon their lives. The unstructured interview was two to three hours in length and elicited information including the following: details around the diagnosis, short and long-term effects upon patient, parents, siblings and family unit, sources of support and the aftereffects of the illness following the ill child's death. The findings showed that siblings experienced the onset of severe enuresis, headaches, poor school performance, severe separation anxieties, feelings of rejection, fear and guilt. The authors concluded that supportive therapy for siblings should be considered an essential aspect of total care of the family.

These early studies are important in that they began to extend the focus of attention on the siblings. However, because of the small sample size, weak research designs, use of psychiatric cases, and major emphasis on post death responses, they have a limited scope of application.

Based on these findings and concerns, researchers began to examine problems in the sibling during illness. Cairns, Clark, Smith and Lansky (1979) were the first researchers to take this new approach. Utilizing an

exploratory design they looked at the impact of childhood cancer both on the patients and their healthy siblings in 71 families. Subjects were conveniently selected at a large medical center. Informed consent was obtained from the parents. Instruments used included the Piers-Harris Children's Self Concept Scale to assess the children's perception of themselves, The Bene-Anthony Family Relations test to assess perceived family roles, and the Thematic Apperception Test (TAT). Scores from the Piers-Harris and Family Relations Test were analyzed using t tests for separate samples and chi-square tests to investigate the possibility of sex differences among the patient or sibling groups. A t test for matched pairs was computed on available data from patient-sibling pairs. TAT scores were analyzed using analysis of variance. A discriminant analysis was also completed to determine whether the subjects could be identified accurately as patients or siblings on the basis of one or more variables in their TAT productions (Cairns, et al., 1979). Enough differences were present to enable the researchers to identify respondents.

Results of the study revealed siblings of children with cancer have significant anxiety and periods of depression. Siblings also feel very isolated from parents, extended family members and friends. On the

Family Relations Test, sex differences were noted with respect to feelings the respondents assign to themselves. The boys in the patient group and the girls in the sibling group did not feel that good feelings, by other family members, were directed toward them.

Recommendations were made to address the needs of the well siblings and to implement specific measures (i.e., encouraging visitations, support groups) to facilitate a healthy adaptation to the situation.

Spinetta (1981) conducted a three year longitudinal study of families with a child diagnosed with cancer, which included 102 siblings. The primary focus of this research was to study siblings in the context of, and in relation to, the family system. The fundamental hypothesis was that siblings suffer at least as much as and probably more than the patients in unattended emotional responses to the disease and disease process. The subjects for the study were the siblings of the children with cancer only and ranged in age from 4 to 18 years. This sample, obtained from a large children's hospital on the West Coast, was one of convenience. Informed consent was obtained from the parents and the siblings in the study. Instruments used to collect data included the Brown IDS Self-Concept Reference Test, Family Relations Test, Roberts Apperception Test and

the Family Environment Scale. The statistical analysis
used was not discussed in the report. The results
showed that siblings' emotional needs were met at a
significantly lower level than other family members.
The author also found several age-related differences on
the dependent variables between the siblings and the ill
child. Siblings age four to six had significantly lower
self concept scores and more negative attitude toward
self than the patients did. They also viewed parents as
psychologically more distant. Siblings age 6-12 years,
had more maladaptive levels of anxiety, depression and
maladaptive responses (e.g., acting out behaviors). The
investigators strongly suggested that sibling adjustment
needed to be addressed by professional caregivers.
Recommendations were made to conduct further studies to
more clearly examine the age-related differences on
sibling adaptation.

Cohen (1985) conducted a study to investigate the
adjustment of siblings to pediatric cancer and of the
variables which may be related to that adjustment. A
sample of 129 families of pediatric cancer patients
participated in the study. Parents were given a series
of mailed questionnaires developed to assess coping,
details of the illness, the level of parent-child
communication, and the adjustment of the sibling closest

in age to the ill child. Siblings were administered a Brother/Sister Questionnaire and the Child Behavior Checklist for ages 4-16. The researcher found that siblings displayed significant adjustment problems when compared to the norms of the Child Behavior Checklist. Significant predictors of sibling adjustment were also identified in the study. These included: parent depression, marital adjustment, annual family income, neighborhood/community social support, parent-sibling communication about the illness, and time since diagnosis.

Recommendations were made to investigate other variables that may be related to coping and that can increase the understanding of and ability to facilitate sibling adjustment to the childhood cancer experience. In addition, it was also suggested that longitudinal studies be done to determine if behaviors that appear maladaptive at the time they occur are in fact healthy and a necessary part of the process of coping.

Although research has identified many negative effects of the cancer experience on healthy siblings, researchers have identified some positive effects as well. The following two studies have found both positive and negative effects of having a sibling with cancer.

Kramer (1981) was the first nurse to study siblings of children with cancer and the first researcher to explore the possible benefits of having a sibling with cancer. This exploratory qualitative study was undertaken to identify the special needs of siblings through their perspective. Eleven siblings of children with cancer made up the sample of convenience. Ages ranged from 7-11 years. Data was obtained from a taped open-ended interview. Content analysis of the data revealed both negative and positive consequences of sibling illness. Negative consequences included emotional stress, senses of emotional deprivation, decrease in parental tolerance, increase in parental expectations, anger and guilt. Positive consequences identified were an increased sensitivity and empathy for the patient and others, enhanced personal maturation and an increased appreciation for life. Further analysis of the data identified three critical factors in facilitating adaptive outcomes. First, siblings wanted information about the disease, treatment and patient's condition. Second, open and honest communication was given essential importance. Finally, all siblings expressed a desire to be actively involved in the sick child's care. Recommendations as to how to meet these needs were suggested by the author. For example,

encourage open communication, expression of feelings, provide information about the disease, encourage participation in the ill child's care.

In a pilot study, Iles (1979), examined the experiences of five healthy siblings of children with cancer during the illness experience. This study was undertaken to determine the feasibility of conducting a longitudinal study examining the same topic. The sample was conveniently selected at a major Southwestern medical center. Subjects ranged in age from 7 to 12 years and their siblings were each in a different stage of the childhood cancer experience. Data was obtained through a taped 45 to 60 minute semi-structured interview. Open-ended questions facilitated discussions of the subject's perceptions regarding family life, the ill sibling and the child himself during current experiences. Subjects were also asked to draw pictures of their families. Taped data were transcribed for analysis and perceptions were tabulated by the researcher and a nurse-social worker from a pediatric-oncology setting. Negative consequences included feelings of loss of quantity and quality of time with parents, changes in family routines and altered peer relationships. Positive consequences noted were increased empathy for parents, respect for the ill child

and improved self concept. Recommendations were made for future research using a longitudinal design.

A study conducted by Koch-Hattem (1986) was designed to increase available information about siblings' perceptions of changes in themselves as well as their families that occur after the diagnosis of pediatric cancer. A sample of 32 siblings were selected after meeting the eligibility criteria set by the researcher. An exploratory quantitative and qualitative approach was utilized. Interviews were conducted in the homes of subjects. The interview schedule contained 30 forced-choice questions related to changes the siblings experienced after the diagnosis was made. In addition, open ended questions were asked exploring how they coped with these changes. Interviews averaged 50 minutes in length.

A single-sample chi-square was used to test for differences among the response choices. The analysis yielded two notable findings. More siblings reported no change in their experiences following the diagnosis than reported either negative or positive changes. The second finding showed a negative change in affect. Siblings described feeling bothered, sad and scared more often after the diagnosis of the illness than before. The results of the study showed that siblings'

perceptions of the cancer experience are organized around affect. Suggestions for future research were similar to those of Iles (1979).

Walker (1988) conducted a qualitative study to identify and describe behavioral and cognitive coping strategies used by siblings. Twenty-six 7 to 11-year-old siblings of pediatric oncology pati·nts and their parents were studied. This sample f convenience was selected from families of pediatric oncology patients being treated at a regional children's hospital. Open-ended interviews with the parents were designed to identify stressors on the family and the effects of these stressors on the sibling(s). The same type of interview with the sibling focused on what the child saw as stressors and what thoughts and behaviors were used to deal with the stressors. Puppet play, family drawings, cartoon story telling and sentence completion tests were used to facilitate communication regarding coping efforts. Content analysis was used to analyze data. The results demonstrated that parents reported physiologic (e.g., weight change, somatic complaints), social (e.g., less desire to play) and affective responses (e.g., acting out, emotional lability) in the siblings. Sibling data reveal three major themes of stressors: loss, fear of death, and change. Coping

strategies used by siblings included wishful thinking, talking to others, attention seeking behaviors and solitary play. Recommendations by the investigator included replication of this research study with a larger and more diverse population.

More recently, Walker et al. (1992) conducted a delphi study to identify and describe nursing behaviors which facilitate the coping efforts of children with cancer and their families. More specifically, the study was conducted to identify what nursing behaviors or interventions nurses believe to be most important in facilitating the patient's, the parents', and the siblings' coping efforts with the effects of the disease of childhood cancer and its treatment. The subjects were a random selection of 300 pediatric oncology nurses from the Association of Pediatric Oncology Nurses (APON). Only nurses completing all three rounds of the study were included in the final sample of 69. The Delphi survey technique involved a series of three rounds of data collection with successive rounds building and refining results from the previous rounds (Walker, et al., 1992).

In the data analysis, all facilitative nursing behaviors identified following round one were listed and reviewed by a collaborative research team. Data

obtained from rounds two and three were analyzed using descriptive statistics. On the round three questionnaire, group means for each nursing behavior were reported. Results demonstrated that open communication was rated as one of the most important facilitative behaviors for patients', parents', and siblings' groups. Other common sibling facilitative behaviors included making siblings feel special, encouraging consistent discipline for all children, and encouraging visits to the hospital/clinic. The authors suggested that the patients, parents and siblings be asked what they believe nurses should do to facilitate their coping with the childhood cancer experience.

In another recent study by Williams (1992) a pilot study was conducted to describe how parents of children with cancer perceive support and the types of interventions they found supportive during their child's hospitalization. In addition, the parents' perceptions of support were compared with those of the health care professionals involved in the care of these children. Seventeen primary caretakers for the ill child and 33 health care professionals involved in the care of these children were studied. Participant observation and in-depth interviews were used to collect data to describe the parents' experiences of parenting a child diagnosed

and being treated for cancer. In-depth interviews were also conducted with the health care professionals to determine their definition of support and what they considered to be supportive to parents during the child's illness.

Analysis of the data was completed through transcribing tape-recorded interviews. Themes pertaining to support were identified using content analysis. Frequency of measures were then tabulated on the content-analyzed data. Results demonstrated that both parents and health professionals identified support similarly in affective terms. Parents defined support as caring, and professionals identified it as being available to parents. Differences between the two groups were based on components of support identified as being more important. Parents identified affective behaviors such as caring, and instrumental support (i.e., assistance with child care) as most important. Health professionals identified affective behaviors (i.e., caring) and educational support as most important. The author recommended that additional research be conducted to examine factors affecting parents' perceptions of support.

Siblings of Handicapped and Chronic..ly Ill Children

Research on siblings of children with developmental disabilities or other chronic medical illnesses suggests that they can be at risk for adjustment problems as is the case in childhood cancer. Although the literature relating to the incidence of psychosocial problems among siblings of handicapped and/or chronically ill children is somewhat contradictory, some similarities with siblings of children with cancer have been noted.

Lavigne and Ryan (1979) compared the psychosocial adjustment of siblings of pediatric cardiology patients, pediatric plastic surgery patients, pediatric hematology patients, and healthy children. The findings of this study suggest that siblings in all three groups were more likely than siblings of the healthy children to experience adjustment or behavior problems. These included social withdrawal, irritability, and fear. In another study, Tew and Laurence (1973) investigated the social adjustment of siblings of children with spina bifida and found very interesting results. Not only were siblings four times more likely to show evidence of maladjustment than siblings of control children, but siblings of slightly handicapped children were more disturbed than siblings of severely handicapped children. In 1980, Taylor conducted a study designed to

elicit descriptions of the effects of long-term childhood illness directly from well siblings. Twenty-five healthy, school aged siblings of children with asthma, congenital heart disease, or cystic fibrosis participated in the study. Findings reported sibling feelings of jealousy, isolation, social withdrawal and loss of parental time and attention.

Despite the fact that evidence exists in the literature to support the fact that siblings of children with handicaps or chronic illness experience difficulties adjusting, such problems are by no means universal. Many siblings of handicapped or chronically ill children do not develop problems and appear to function effectively under stress. Several studies throughout the literature have reported positive effects on siblings of handicapped or chronically ill children. Studies by Siemon (1984), McKeever (1983) and Simeonsson (1981) identified that while being a sibling of a disabled or ill child can create vulnerabilities, it can also engender strength, sensitivity, compassion and empathy. In addition, although Taylor (1980) noted the negative impact of handicap or illness on siblings, she also noted that there are benefits that accrue to the siblings. For example, she noted increased levels of

maturity and responsibility, sensitivity, and compassion.

In conclusion, siblings of children with handicaps and chronic illnesses, other than cancer, may also be at increased risk for maladaptive adjustment. Although extensive research has been done in this area of chronic illness and sibling response, as compared to childhood cancer, many problem areas have been noted and have contributed to research efforts that are conflicting. Studies of siblings of children with cancer, as well as research in other areas of chronic illnesses, should focus on interventions in clinical practice to reduce the incidence of maladaptive outcomes. In addition, more knowledge is needed about what specific variables predispose a sibling to long-term difficulties with adjustment and how these change over time.

Conceptual Framework

Psychosocial adjustment to the childhood cancer experience has been described throughout the literature as a process of familial emotional events to be overcome (Morrow, Hoagland and Carnrike, 1981). Social support has been viewed as a potentially protective element in dealing with the effects of these stressful events. It was during the early 1970's that the concept of social support first emerged. Social support was found to be beneficial to health and well being, either directly or because it moderates the effects of stress on individual health and well being (House, 1981).

Over the past two decades, there have been a sizeable number of studies conducted that suggest the importance of social support for moderating the physical and psychological distress related to the severe stressors associated with serious illnesses such as cancer. Cancer, because of its unpredictable nature and lengthy treatment process, is regarded as an ongoing stressor that requires continual physical and psychosocial adjustments, not only by the patient but by the family as well. Social support, for the purpose of this study, as defined by House (1981) is an interpersonal transaction involving one or more of the following: (1) emotional support, which involves

providing empathy, encouragement, understanding, caring, love and trust, (2) instrumental support, providing direct help or material aid to help other people do their work, take care of themselves or help them financially, (3) informational support, providing information or guidance to help a person better understand and adjust to changes in his/her life, and (4) appraisal support, pertaining to self evaluation; acknowledging that one's beliefs and interpretations of a situation are appropriate. Such support can come from a variety of people including a spouse or partner, other family members, friends or professional caregivers.

Social support can be beneficial to siblings of children with cancer in helping them to deal with the psychosocial demands of having a brother or sister with cancer. Social support has been found to be a strong resource for adjusting to the cancer experience. In 1984, Morrow, Carpenter and Hoagland studied 107 parents of children with cancer. The purpose of this study was to examine the effects of social support on the psychosocial problems of the family when a child is being treated for cancer. Results of the study showed that social support was related to positive psychosocial adjustment, particularly for parents whose child was

currently receiving treatment. Parents whose child had died did not appear to benefit from any source of social support. In another study by Bloom (1982), adult cancer patients identified that they had enhanced needs for social support to help them deal with the fears and uncertainties related to their illness. Furthermore, they felt these needs can often be met by such caregivers as physicians and nurses. Morrow, Hoagland and Carnrike (1981) also found that the psychosocial adjustment of parents of children with cancer was significantly related to parents' perceived support not only from spouses but also from relatives, friends, other parents with ill children and health care providers. More recently, La Montagne and Pawlack (1990) studied parents of children in pediatric intensive care units. Findings showed that social support was a frequently used coping strategy. The authors recommended that clinicians assess who is supportive for the parents and emphasized that ongoing support may be especially important in helping them adjust to the stress of the experience.

The literature has identified that health care professionals can provide high quality social support for families of children with cancer (Ross, 1978). In a study by Dunkel-Shetter (1984), physicians, nurses and

other health care providers were mentioned about as frequently as family members as sources of support. Similarly, Morrow, Hoagland, and Morse (1982) found that a large number of parents reported health care professionals as being supportive during their child's illness.

Research in the area of social support has also shown that specific types of support are better provided by certain individuals. Dunkel-Shetter (1984) found in her study that although respondents found family, friends, and caregivers to be helpful in providing support, different types of support were more valuable when received from certain individuals. Emotional support was rated by cancer patients as being most helpful (81% of respondents) followed by informational support (41% of respondents). Instrumental and appraisal support were rated as less helpful (each by 6% of respondents). The most surprising finding was that emotional support was found to be equally helpful whether it came from family, friends, or health care providers. Furthermore, lack of emotional support from health care providers was seen as unhelpful. Informational support was perceived as helpful if it was provided by health care providers, and perceived as unhelpful if it was provided by family and friends.

Clearly, social support can be beneficial to siblings of children with cancer, as it is with patients with cancer, by altering the demands of the illness as perceived by the sibling. When one looks at the positive outcomes of social support, in relation to the extent to which it meets the needs of individuals by either decreasing the demands of illness or increasing availability of resources, it becomes obvious that social support is essential in providing care to siblings.

During the childhood cancer experience, parents struggle with the demands of conjoint allocation of time and energies to ill children and their siblings. More often than not, parents end up spending much more of their time at the hospital. When they are at home they are often tired, stressed and distracted. Eventually the entire family structure becomes disrupted. Siblings are often overlooked in the process. Their questions go unanswered, they develop fears and anxieties, and begin to withdraw from their family and social groups. Siblings need someone with whom they can express their feelings and emotions. They need the opportunity to cry, to laugh, and be happy. The siblings in this family crisis need to know that even though their parents spend more time with the ill child, they are

still loved and cared about despite what is happening in their family during the painful experience of childhood cancer (Snyder, 1986).

Extended family members and/or community agencies can serve as helpful agents for providing instrumental support. Many siblings wish that their lives could return to normal. It is important to keep life as close to normal as possible. The well children should be encouraged to attend social activities, sport events and/or continue with hobbies. Support networks, such as family, friends and neighbors, are needed to help siblings continue with life as usual. Assistance such as providing child care and transportation to activities can contribute to meeting sibling needs of instrumental support.

Interventions aimed at reducing maladaptive responses and promoting adaptive coping by siblings of a child with cancer must include informational support. When siblings' questions go unanswered, they often fantasize about what is happening with the ill child in the hospital. They often fear that they caused the disease or that they may catch it themselves. If the child is old enough to ask the question, he or she is old enough to receive an honest answer. Information provided should cover the disease, treatments, side

effects, prognosis as well as changes that could occur in the family during the childhood cancer experience. It is important to emphasize the disease is not contagious, that the cause in unknown, and that the sibling was not responsible for the ill brother or sister developing cancer.

Finally, appraisal support can help siblings to examine the situation closely and interpret it more appropriately. This will help to dispel any fears and misconceptions they may have.

Conclusion

Social support appears to be beneficial in the positive psychosocial adjustment of patients with cancer and of parents of children with cancer. Also, siblings of children with cancer often do not receive adequate support during the illness experience. The role of social support in decreasing the demands of the childhood cancer experience, can have a positive outcome with siblings of children with cancer as well. Supporting siblings during this potentially traumatic experience requires not only recognition of the complexity of the illness experience but also the usefulness of social support interventions.

Siblings need support throughout the course of the illness and treatment as do parents and patients.

Support is required for meeting emotional, instrumental, informational, and appraisal needs. It is important in delivering comprehensive family-centered care, to provide psychosocial care to the siblings of children with cancer as well. Nurses working in the pediatric oncology clinical setting are in ideal positions to utilize interventions aimed at providing social support to siblings.

Assumptions

The major assumption for the study is as follows:
(1) Subjects will respond honestly to questionnaire items.

Chapter 3

Methodology

Subjects

Criteria for subjects' inclusion in the study were:
(1) the nurses have at least 12 months of pediatric
oncology nursing experience and (2) be currently working
in pediatric oncology nursing. The subjects were 134
Registered Nurses who were current members of the
Association of Pediatric Oncology Nurses (APON). The
respondents were all female. They ranged in age from 27
years to 67 years, with an average age of 39 years (S.D.
= 7.35) (Table 1). Most subjects held either a Master's
(64.9%) or a Bachelor's (26.9%) degree (Table 2).
Although the respondents worked in a variety of practice
settings, the majority listed work sites as either
inpatient medical centers (32.8%) or outpatient clinics
(31.3%) (Table 3). In analyzing functional areas of
practice, 86.6% of nurses worked in patient care, with
the remainder reporting other functional areas (Table
4). The more common practice responsibilities were
clinical nurse specialist (38.1%), staff nurse (30.6%)
and pediatric nurse practitioner (15.7%) (Table 5). The
average number of years of pediatric oncology nursing

experience was 13, and the average number of years of general pediatric nursing experience was 15 (Table 6).

Table 1

Subjects' Age Distribution

Age in Years	N	%
25-30	5	3.7
31-35	49	36.6
36-40	32	23.9
41-45	25	18.7
over 45	22	16.4
missing value	1	0.7
	134	100

Table 2

Education

Degree	N	%
Diploma	5	3.7
Associate Degree	3	2.2
Bachelor's Degree	36	26.9
Master's Degree	87	64.9
Doctoral Degree	1	0.7
Non Nursing Degree	2	1.5
	134	100

Table 3

Practice Setting

Setting	N	%
Inpatient Medical Center	44	32.8
Inpatient Community Hospital	2	1.5
Inpatient Bone Marrow Transplant Unit	8	ˋ
Combination Oncology/Bone Marrow Transplant Unit	16	11.9
Combination Oncology/Pediatric Unit	16	11.9
Outpatient Clinic	42	31.3
Other	6	4.5
	134	100

Table 4

Functional Area of Practice

Functional Area	N	%
Patient Care	116	86.6
Education	4	3.0
Research	1	0.7
Administration	12	9.0
Other	1	0.7
	134	100

Table 5

Practice Responsibilities

Position	N	%
Staff Nurse	41	30.6
Clinical Nurse Specialist	51	38.1
Educator	3	2.2
Supervisor	2	1.5
Head Nurse	10	7.5
Pediatric Nurse Practitioner	21	15.7
Administrator	5	3.7
Missing Value	1	0.7
	134	100

Table 6

General and Pediatric Oncology Nursing Experience

	Pediatric Nursing		Pediatric Oncology Nursing	
Years	N	%	N	%
1-3	0	0.0	0	0.0
4-5	2	1.5	3	2.2
6-10	23	17.2	46	34.3
11-15	57	42.5	56	41.8
16-20	29	21.6	20	14.9
over 20	23	17.2	9	6.7
	134	100	134	100

Measures

Each subject chosen at random to participate received a packet containing a cover letter, Demographic Information Sheet, Sibling Social Support Questionnaire, and a postage-paid return envelope.

Cover letter. The cover letter (Appendix A) identified the purpose of the present study and explained how participants were chosen to receive packets. Information included response time frames and provided telephone numbers of individuals to call for any questions. The cover letter thanked the participants for participating in the study if they chose to do so.

Demographic Information Sheet. The Demographic Information Sheet (Appendix B) is a questionnaire developed by the investigator for the purpose of this study, to obtain demographic information of the sample on the following categories: (a) age, (b) sex, (c) children, (d) number of children, (e) educational degree, (f) practice setting, (h) position (practice responsibility), (i) size of unit, (j) hours performing direct patient care, (k) years of pediatric oncology experience and (f) years of pediatric nursing experience.

Instrument

Sibling Social Support Questionnaire. The Sibling
Social Support Questionnaire (SSSQ) (Appendix C) is a
questionnaire developed by the investigator, for the
current study. The instrument is a 30-item, Likert
scale instrument. This self-report measure asked
respondents to indicate the extent to which they include
each of 30 nursing intervention items in their current
practice. Ratings range from Never (1) to Always (4).

The items in the questionnaire were derived from an
extensive review of the literature in the fields of
nursing, medicine, psychology and sociology. Much of
the research done over the past 30 years has included
recommendations of interventions to use in practice with
siblings of children with cancer. These
recommendations, along with suggestions from clinical
experts in the field of pediatric oncology nursing, were
used to develop the questionnaire. Reliability testing
on the instrument, with the sample of 134 pediatric
oncology nurses, was conducted using Cronbach's
coefficient alpha. The alpha was equal to 0.95
indicating a high degree of internal consistency of the
instrument. In determining the content validity of the
instrument, ten clinical experts in pediatric oncology
nursing were selected to evaluate the content of each

item of the tool. Consensus was reached when all of the experts reported that the instrument was comprehensive regarding appropriate interventions. Factor analysis was planned to determine construct validity of the instrument. However, due to the small sample size, adequate construct validity testing was not feasible.

Page three of the questionnaire includes a section for general comments. This section was included to provide an opportunity for respondents to share any thoughts, feelings, or concerns about the questionnaire and topic of study. Respondents are also asked to share interventions they use in clinical practice to help siblings of children with cancer cope with the childhood cancer experience. Responses from this page were analyzed for recurring themes or regularities. A multiple-perspective approach was employed to minimize biases. Three experts in pediatric nursing completed thematic analyses of the data. Results were used to qualify quantitative data and are presented in Chapter 5.

Procedures

Names of potential subjects were obtained from the Association of Pediatric Oncology Nurses (APON) following permission for access from the president of the organization. Two lists of 250 randomly selected

member names and addresses, printed on labels, were acquired from the central office in Richmond, Virginia.

On January 1, 1993, 250 registered nurses were mailed a cover letter explaining the study (Appendix A), Demographic Information Sheet (Appendix B), and the Sibling Social Support Questionnaire (Appendix C). The participants were asked to return the Demographic Information Sheet and Sibling Social Support Questionnaire in an enclosed postage-paid return envelope by February 1, 1993. Reminder letters were to be mailed out on January 22, 1993 if the response rate was below forty percent.

Of the 250 research study packets mailed out, 163 (65%) were completed and returned. Of the 163 questionnaires, 134 met the criteria for inclusion and therefore were included in the analysis.

Risks to Subjects

There were no known or anticipated risks in the study. The cover letter, demographic information sheet and questionnaire were designed to be as non-threatening as possible. This study was anonymous. The investigator had no way of knowing which questionnaires belonged to what respondent. Having duplicate mailing labels for the purpose of reminder

letters served to protect the anonymity of participants throughout the study.

Potential Benefits to Subjects

Participants may have directly benefitted from participation in this study by possibly developing insight into their own practice of providing social support to siblings of children with cancer. The subjects may have also found that their participation in this study presented a therapeutic opportunity to express their thoughts and feelings about the topic under investigation. The information obtained from the subjects will be instrumental in the future in planning nursing interventions for siblings of children with cancer.

Design and Statistical Analysis

This was an exploratory descriptive study which used descriptive statistical analyses to look at each item score. Group means for the frequency of use of each nursing intervention were computed initially. Means tables were produced to look at the average use (mean value) of each of the 30 nursing intervention items of the Sibling Social Support Questionnaire (SSSQ) in order to create a rank order list of most frequently used interventions by educational degree, years of pediatric nursing experience and practice responsibility.

Simple regression analysis was used to assess the relationship between the variables of: (1) educational degree, (2) years of general pediatric experience, (3) position (practice responsibility) and Sibling Social Support Questionnaire responses.

Limitations of Study

Limitations of the current study include:

(1) sample size ($N = 134$)

(2) social desirability response

(3) generalizability of results

Pilot Testing

Before conducting this study, pilot testing of the tools and procedures was completed. Research tools were mailed to 50 registered nurses who were members of the Association of Pediatric Oncology Nurses (APON). Twenty-five (50%) were completed and returned. A reliablity analysis yielding a Cronbach alpha coefficient was performed on the Sibling Social Support measure created for the study. Testing resulted in a Cronbach alpha of 0.90. Nursing interventions identified as the most commonly used by Pediatric Oncology Nurses in working with siblings of children with cancer were the same as the current study and therefore are presented in Chapter 4.

Chapter 4

Results

Descriptive Analysis

Descriptive statistics of the frequency of intervention use were computed and ranked for the entire sample (Table 7). The mean scores representing frequency of use ranged from 2.33 to 3.78 out of a total score of 4.00. The ten most commonly used interventions in clinical practice by pediatric oncology nurses included:

(1) Encourage parents to spend time with their other children;

(2) Provide honest responses to questions asked by siblings;

(3) Encourage parents to bring siblings to hospital;

(4) Reassure siblings they will not catch illness;

(5) Encourage siblings to ask questions;

(6) Reassure siblings they did not cause illness;

(7) Encourage a balance in family life so that the focus is not continually on ill child;

(8) Encourage expression of feelings by siblings;

(9) Provide parents with anticipatory guidance for potential areas of difficulty with siblings and

(10) Acknowledge positive behaviors/accomplishments of siblings.

The most frequently utilized interventions are directed at meeting the emotional and informational needs of siblings. This study identified open communication, involvement of the sibling in the childhood cancer experience, acknowledging sibling needs and providing anticipatory guidance as being the most significant nursing interventions in the care of siblings.

Table 7

Nursing Interventions Providing Social Support

Mean	Rank	Intervention
3.78	1.	Encourage parents to spend time with their other children.
3.74	2.	Provide honest responses to questions asked by siblings.
3.70	3.	Encourage parents to bring siblings to hospital.
3.65	4.	Reassure siblings they will not catch illness.
3.61	5.	Encourage siblings to ask questions.
3.58	6.	Reassure siblings they did not cause illness.
3.53	7.	Encourage a balance in family life so focus is not continually on ill child.
3.44	8.	Encourage expression of feelings by siblings.
3.41	9.	Provide parents with anticipatory guidance for potential areas of difficulty with siblings.
3.40	10.	Acknowledge positive behaviors of siblings.
3.33	11.	Encourage parents to discuss death with siblings.

Table 7 (cont.)

3.25　12. Provide assistance to parents to facilitate
　　　　　their ability to meet the psychosocial needs
　　　　　of their other children.

3.23　13. Encourage parents to include siblings in
　　　　　bereavement groups.

3.16　14. Encourage participation of siblings in ill
　　　　　child's care.

3.15　15. Encourage parents to explain changes in the
　　　　　family system to their well children.

3.13　16. Crient siblings to pediatric/pediatric
　　　　　oncology unit.

3.12　17. Facilitate supportive relationships between
　　　　　siblings and hospital staff.

3.07　18. Educate siblings about the disease based on
　　　　　developmental level.

3.02　19. Nurse encourages siblings to attend
　　　　　bereavement group.

2.96　20. Provide advanced information to siblings as
　　　　　their developmental level increases.

2.95　21. Consider siblings when formulating care plan.

2.87　22. Prepare siblings for changes that may occur.

2.86　23. Identify formal and/or informal networks for
　　　　　siblings (i.e., peer support groups).

Table 7 (cont.)

2.82   24. Update siblings on ill child's progress.

2.81   25. Provide siblings with reference materials.

2.54   26. Nurse discusses concept of death with
            siblings.

2.53   27. Include siblings in subsequent conferences.

2.52   28. Educate community agencies about their
            potential role in helping to meet the social
            and emotional needs of siblings.

2.47   29. Counsel parents about research findings
            pertaining to responses of siblings.

2.33   30. Include siblings in initial family conference
            at the time of diagnosis.

Educational Level and Use of Interventions.

Descriiptive statistical analyses were performed comparing the educational levels of the subject groups and the types and frequency of use of interventions aimed at providing social support to siblings. Many of the interventions identified as being utilized more frequently by the entire group of subjects, were also identified by subjects in all levels of educational preparation. Although there was some variation in the ranking of these interventions, nurses in all educational groups consistently identified encouraging parents to spend time with their other children and providing honest responses to questions asked by siblings, as the two most important interventions. Differences, although few, included the use of the intervention of educating community agencies about their potential role in helping to meet the social and emotional needs of siblings. Diploma prepared subjects (N = 5) (Table 8) identified this intervention as one of the ten most commonly used. In contrast, this intervention was not included in the list of most commonly used interventions by Associate Degree nurses (Table 9), Bachelor Degree nurses (Table 10), Master Degree nurses (Table 11), or the Doctorally prepared nurse (Table 12). Interestingly enough, the same

intervention was ranked as one of the most infrequently used by these same groups of subjects. Analyses of the least frequently used interventions also provided similar findings. Nurses with all levels of educational preparation identified the same interventions used with the lowest level of frequency. For example, subjects in all groups specified interventions such as including siblings in initial and subsequent family conferences and counseling parents about research findings pertaining to responses of siblings, as being the least frequently used interventions in their own clinical practice. Overall, subjects across all educational levels utilized similar types of interventions, providing emotional and informational support, with the same degree of importance. Data of the mean scores of interventions utilized by educational degree are presented in Table 13.

To summarize, comparisons between the groups indicated that there were similarities between specific interventions identified as being most important and used more frequently independent of educational level. However, some differences were noted on the ranking of certain interventions and the use of a select intervention based on educational level. It is important to note the sample size of each group. Having

a larger N in some of the educational groups relative to the larger groups, would have been especially desirable in order to increase the potential generalizability of the results.

Table 8

Ten Most Commonly Used Social Support Interventions

by Diploma Nurses (N = 5)

Mean	Intervention
4.00	- Encourage parents to spend time with their other children.
	- Provide honest responses to questions asked by siblings.
3.80	- Encourage a balance in family life so focus is not continually on ill child.
	- Provide parents with anticipatory guidance for areas of difficulty with siblings.
3.60	- Encourage parents to bring siblings to hospital.
	- Acknowledge positive behaviors of siblings.
	- Encourage parents to explain changes in family system to their well children.
3.40	- Encourage siblings to ask questions.
	- Encourage parents to discuss death with siblings.
3.25	- Educate community agencies about their potential role ir helping to meet the social and emotional needs of siblings.

Table 9

Ten Most Commonly Used Social Support Interventions by
Associate Degree Nurses (N = 3)

Mean	Intervention
4.00	- Encourage parents to spend time with their other children.
	- Provide honest responses to questions asked by siblings.
	- Reassure siblings they will not catch illness.
	- Encourage siblings to ask questions.
	- Reassure siblings they did not cause illness.
	- Encourage a balance in family life so focus is not continually on ill child.
	- Provide parents with anticipatory guidance for potential areas of difficulty with siblings.
	- Encourage parents to discuss death with siblings.
	- Educate siblings about the disease based on developmental level.
3.67	- Encourage parents to bring siblings to hospital.

Table 10

Ten Most Commonly Used Social Support Interventions
by Bachelor Degree Nurses (N = 36)

Mean	Intervention
3.79	- Encourage parents to spend time with their other children.
3.61	- Provide honest responses to questions asked by siblings.
3.58	- Reassure siblings they will not catch illness.
	- Reassure siblings they did not cause illness.
3.57	- Encourage parents to bring siblings to hospital.
3.47	- Encourage siblings to ask questions.
3.44	- Encourage a balance in family life so focus is not continually on ill child.
3.33	- Provide parents with anticipatory guidance for potential areas of difficulty with siblings.
3.31	- Encourage parents to discuss death with siblings.
3.28	- Encourage expression of feelings by siblings.

Table 11

Ten Most Commonly Used Social Support Interventions

by Masters Degree Nurses (N = 87)

Mean	Intervention
3.77 -	Provide honest responses to questions asked by siblings.
3.76 -	Encourage parents to spend time with their other children.
3.74 -	Encourage parents to bring siblings to the hospital.
3.69 -	Reassure siblings they will not catch illness.
3.66 -	Encourage siblings to ask questions.
3.59 -	Reassure siblings they did not cause illness.
3.53 -	Encourage a balance in family life so focus is not continually on ill child.
3.49 -	Encourage expression of feelings by siblings.
3.41 -	Provide parents with anticipatory guidance for potential areas of difficulty with siblings.
	- Acknowledge positive behaviors of siblings.

Table 12

Ten Most Commonly Used Social Support Interventions
by Doctorate Nurse (N = 1)

Mean   Intervention

4.00 - Encourage parents to spend time with their other
       children.

     - Provide honest responses to questions asked by
       siblings.

     - Encourage parents to bring siblings to hospital.

     - Reassure siblings they will not catch illness.

     - Encourage siblings to ask questions.

     - Reassure siblings they did not cause illness.

     - Encourage a balance in family life so focus is
       not continually on ill child.

     - Encourage expression of feelings by siblings.

     - Provide parents with anticipatory guidance for
       potential areas of difficulty with siblings.

     - Acknowledge positive behaviors of siblings.

Table 13

Educational Degree and Mean Value for Intervention Use

	Diploma n = 5	AD n = 3	BSN n = 36	Masters n = 87	Doctorate n = 1
Nursing careplan	3.20	3.00	2.72	3.01	4.00
Family conference	2.20	3.50	2.25	2.36	2.00
Subsequent conferences	2.60	2.00	2.47	2.59	3.00
Visit hospital	3.60	3.67	3.57	3.74	4.00
Orient to unit	3.00	3.33	3.21	3.07	4.00
Educate about disease	3.20	4.00	3.08	3.00	4.00
Participation in care	2.40	3.67	3.11	3.17	4.00
Update on progress	2.00	2.33	2.75	2.90	3.00
Provide advanced information	2.60	3.00	2.89	3.00	3.00
Prepare for changes	2.20	2.67	2.75	2.93	3.00
Identify support network	3.00	3.33	2.75	2.86	4.00
Facilitate supportive relationships	2.80	2.67	2.83	3.24	4.00
Encourage expression of feelings	3.20	3.67	3.28	3.49	4.00
Encourage questions	3.40	4.00	3.47	3.66	4.00
Provide honest responses	3.80	4.00	3.61	3.77	4.00
Acknowledge positive behaviors	3.60	3.67	3.28	3.41	4.00
Parent/sibling bereavement group	2.60	3.33	3.14	3.29	3.00
Nurse/sibling bereavement group	2.40	3.33	2.80	3.14	3.00
Parental anticipatory guidance	3.80	4.00	3.33	3.41	4.00
Encourage time with other children	4.00	4.00	3.79	3.76	4.00
Parental assistance	3.20	3.67	3.08	3.30	4.00
Educate community agencies	3.25	1.50	2.22	2.62	3.00
Changes in family system	3.60	2.67	2.89	3.24	4.00
Family balance	3.80	4.00	3.44	3.53	4.00
Discuss death	2.20	2.67	2.44	2.59	3.00
Illness cause	3.20	4.00	3.58	3.59	4.00
Catch illness	3.20	4.00	3.58	3.69	4.00
Parents discuss death	3.40	4.00	3.31	3.33	4.00
Reference materials	3.20	3.00	2.56	2.85	4.00
Research findings	2.20	2.50	2.17	2.62	4.00

Years of Pediatric Nursing Experience and Use of
Interventions.

Further analysis of the data, according to total
number of years of pediatric nursing experience of the
subjects, displayed significant similarities and some
minor differences as well. The interventions used with
the highest level of frequency were once again
identified as being the most important independent of
the number of years of pediatric nursing experience of
subjects. As with educational level, the ranking of
interventions was variable to some degree. For example,
nurses with 11-15 years of pediatric experience (N = 57)
(Table 16) ranked the intervention of encouraging a
balance in family life so focus is not continually on
the ill children as #8 and nurses with 21-25 years of
pediatric experience (N = 15) (Table 18) ranked the
intervention as #1, the most important.

Differences among groups although small, deserve
mentioning. Nurses with 1-5 years (N = 2) (Table 14)
and greater than 25 years of nursing experience (N = 8)
(Table 19) ranked the intervention of facilitating a
supportive relationship between siblings and hospital
staff among the top ten frequently used interventions.
Nurses in the other group ranked this intervention in
the 11-20 range or the second group of most frequently

used interventions. Providing assistance to parents to facilitate their ability to meet the psychosocial needs of their other children was ranked in the top ten by nurses with 6-10 years of pediatric experience (N = 23) (Table 15). All other groups ranked this intervention in the 11-20 range. Although nurses with 1-5 years of pediatric experience (N = 2) (Table 14) ranked encouraging both parents and nurses to include siblings in bereavement groups, other subjects in the study ranked this intervention lower. Finally, nurses with 11-15 years of pediatric experience (N = 57) (Table 16) and 21-25 years of pediatric experience (N = 15) (Table 18) ranked encouraging parents to discuss death with siblings high, were as other groups ranked the same intervention in the 11-20 group of interventions. Differences among groups centered around providing different types of emotional and informational support. A complete listing of results yielded is presented in Table 20.

Table 14

Ten Most Commonly Used Social Support Interventions by

Nurses with 1-5 Years of Pediatric Nursing Experience

(N = 2)

Mean	Intervention
4.00	- Provide honest responses to questions asked by siblings.
	- Encourage siblings to ask questions.
	- Encourage expression of feelings by siblings.
	- Acknowledge positive behaviors of siblings.
	- Facilitate supportive relationships between siblings and hospital staff.
3.50	- Encourage parents to spend time with their other children.
	- Encourage parents to bring siblings to hospital.
	- Reassure siblings they will not catch illness.
	- Encourage parents to include siblings in bereavement group.
	- Nurse encourages siblings to attend bereavement group.

Table 15

Ten Most Commonly Used Social Support Interventions

by Nurses with 6-10 Years of Pediatric Nursing

Experience (N = 23)

Mean	Intervention
3.70	- Encourage parents to spend time with their other children.
3.57	- Provide honest responses to questions asked by siblings.
	- Encourage parents to bring siblings to the hospital.
3.48	- Encourage siblings to ask questions.
	- Reassure siblings they will not catch illness.
3.43	- Reassure siblings they did not cause illness.
3.35	- Encourage a balance in family life so focus is not continually on ill child.
3.26	- Acknowledge positive behaviors of siblings.
3.17	- Provide parents with anticipatory guidance for potential areas of difficulty with siblings.
3.13	- Provide assistance to parents to facilitate their ability to meet the psychosocial needs of their other children.

Table 16

Ten Most Commonly Used Social Support Interventions by
Nurses with 11-15 Years of Pediatric Nursing Experience
(N = 57)

Mean	Intervention
3.88	- Provide honest responses to questions asked by siblings.
3.81	- Encourage parents to spend time with their other children.
3.77	- Encourage parents to bring siblings to hospital.
3.70	- Reassure siblings they will not catch illness.
3.67	- Encourage siblings to ask questions.
3.65	- Reassure siblings they did not cause illness.
3.61	- Encourage expression of feelings by siblings.
3.50	- Encourage a balance in family life so focus is not continually on ill child.
3.48	- Encourage parents to discuss death with siblings.
3.47	- Provide parents with anticipatory guidance for potential areas of difficulty with siblings.

Table 17

Ten Most Commonly Used Social Support Interventions by
Nurses with 16-20 years of Pediatric Nursing Experience
(N = 29)

Mean	Intervention
3.83 -	Encourage parents to spend time with their other children.
3.75 -	Encourage parents to bring siblings to hospital.
3.72 -	Reassure siblings they will not catch illness.
3.69 -	Reassure siblings they did not cause illness.
3.62 -	Provide honest responses to questions asked by siblings.
3.55 -	Encourage siblings to ask questions.
-	Provide parents with anticipatory guidance for potential areas of difficulty with siblings.
3.52 -	Encourage a balance in family life so focus is not continually on ill child.
3.41 -	Encourage expression of feelings by siblings.
3.34 -	Acknowledge positive behaviors of siblings.

Table 18

Ten Most Commonly Used Social Support Interventions

by Nurses with 21-25 Years of Pediatric Nursing

Experience (N = 15)

Mean	Intervention
3.87	- Encourage a balance in family life so focus is not continually on ill child.
3.80	- Encourage parents to spend time with their other children.
3.67	- Provide honest responses to questions asked by siblings.
3.60	- Encourage parents to bring siblings to hospital.
3.53	- Encourage siblings to ask questions.
	- Reassure siblings they will not catch illness.
3.47	- Reassure sibling they did not cause illness.
3.40	- Provide parents with anticipatory guidance for potential areas of difficulty with siblings.
	- Acknowledge positive behaviors of siblings.
	- Encourage parents to discuss death with siblings.

Table 19

Ten Most Commonly Used Social Support Interventions by
Nurses with > 25 Years of Pediatric Nursing Experience
(N = 8)

Mean	Intervention
3.88	- Encourage siblings to ask questions.
	- Encourage a balance in family life so focus is not continually on ill child.
3.75	- Encourage parents to spend time with their other children.
	- Provide honest responses to questions asked by siblings.
	- Reassure siblings they will not catch illness.
	- Encourage expression of feelings by siblings.
3.63	- Encourage parents to bring siblings to hospital.
3.50	- Reassure siblings they did not cause illness.
	- Acknowledge positive behaviors of siblings.
	- Facilitate supportive relationship between siblings and hospital staff.

Table 20

Years of Pediatric Nursing Experience and Mean Value for Intervention Use

	1-5 years n=2	6-10 years n=23	11-15 years n=57	16-20 years n=29	21-25 years n=15	26+ years n=8
Nursing careplan	2.50	2.52	3.00	3.04	3.13	3.25
Family conference	3.00	2.22	2.28	2.30	2.47	2.63
Subsequent conferences	3.00	2.26	2.49	2.59	2.87	2.75
Visit hospital	3.50	3.57	3.77	3.75	3.60	3.63
Orient to unit	3.00	3.00	3.22	2.85	3.33	3.50
Educate about disease	3.00	2.87	3.12	2.90	3.33	3.38
Participation in care	3.00	2.87	3.28	3.17	3.27	2.88
Update on progress	3.00	2.57	2.95	2.79	2.80	2.75
Provide advanced information	3.50	2.61	3.11	2.79	3.00	3.38
Prepare for changes	3.00	2.52	3.00	2.76	2.93	3.13
Identify support network	3.50	2.52	2.91	2.83	3.13	2.88
Facilitate supportive relationships	4.00	2.74	3.21	3.14	3.00	3.50
Encourage expression of feelings	4.00	3.00	3.61	3.41	3.27	3.75
Encourage questions	4.00	3.48	3.67	3.55	3.53	3.88
Provide honest responses	4.00	3.57	3.88	3.62	3.67	3.75
Acknowledge positive behaviors	4.00	3.26	3.44	3.34	3.40	3.50
Parent/sibling bereavement group	3.50	3.04	3.39	3.11	3.40	2.63
Nurse/sibling bereavement group	3.50	2.65	3.20	2.96	3.20	2.63
Parental anticipatory guidance	3.00	3.17	3.47	3.55	3.40	3.38
Encourage time with other children	3.50	3.70	3.81	3.83	3.80	3.75
Parental assistance	3.50	3.13	3.30	3.17	3.40	3.25
Educate community agencies	1.50	2.26	2.57	2.36	3.14	2.63
Changes in family system	3.00	2.91	3.16	3.17	3.27	3.50
Family balance	3.00	3.35	3.50	3.52	3.87	3.88
Discuss death	2.00	2.22	2.57	2.64	2.73	2.63
Illness cause	3.00	3.43	3.65	3.69	3.47	3.50
Catch illness	3.50	3.48	3.70	3.72	3.53	3.75
Parents discuss death	3.00	3.09	3.48	3.32	3.40	3.00
Reference materials	2.50	2.52	2.86	2.76	3.20	2.75
Research findings	2.50	2.13	2.43	2.39	2.87	3.25

Practice Responsibility and Use of Interventions

The final analysis of data from this study was evaluated according to practice responsibilities in the clinical setting. The three practice responsibilities compared in detail for the purpose of this study were the Staff Nurse (N = 41), Pediatric Clinical Nurse Specialist (N = 51), and Pediatric Nurse Practitioner (N = 21). Results indicated that subjects in all three groups utilized almost all of the same interventions identified by the entire sample as being used with the highest level of frequency. Ranking once again was variable, but the same interventions were identified. The only difference found was that the Clinical Nurse Specialist (Table 22) ranked encouraging parents to discuss death with siblings in the top ten most commonly used interventions. Staff Nurses (Table 21) and Pediatric Nurse Practitioners (Table 23) did not rank this intervention in the top ten, but did rank it shortly thereafter.

In examining the interventions used with the least amount of frequency, all three groups ranked including siblings in the initial and subsequent family conferences, educating community agencies about their potential role in helping to meet the social and emotional needs of siblings, and counseling parents

about research findings pertaining to responses of siblings, lowest on the list.

In summary, nurses, independent of practice responsibility, used the same type of social support interventions when working with siblings of children with cancer in clinical practice. The results yielded are presented in Table 24.

Table 21

Ten Most Commonly Used Social Support Interventions

Used by Staff Nurses (N = 41)

Mean	Intervention
3.80	- Encourage parents to spend time with their other children.
3.68	- Provide honest responses to questions asked by siblings.
3.61	- Encourage parents to bring siblings to the hospital.
3.59	- Reassure siblings they will not catch illness.
3.56	- Encourage siblings to ask questions.
	- Reassure siblings they did not cause illness.
3.46	- Encourage a balance in family life so focus is not continually on ill child.
3.44	- Acknowledge positive behaviors of siblings.
3.34	- Encourage expression of feelings by siblings.
	- Provide parents with anticipatory guidance for potential areas of difficulty with siblings.

Table 22

Ten Most Commonly Used Social Support Interventions by Pediatric Clinical Nurse Specialists (N = 51)

Mean	Intervention
3.82	- Encourage parents to bring siblings to hospital.
3.78	- Provide honest responses to questions asked by siblings.
3.76	- Encourage parents to spend time with their other children.
3.73	- Reassure siblings they will not catch illness.
3.65	- Reassure siblings they did not cause illness.
	- Encourage siblings to ask questions.
3.57	- Encourage a balance in family life so focus is not continually on ill child.
	- Provide parents with anticipatory guidance for potential areas of difficulty with siblings.
3.47	- Encourage expression of feelings by siblings.
3.43	- Encourage parents to discuss death with siblings.

Table 23

Ten Most Commonly Used Social Support Interventions

by Pediatric Nurse Practitioners (N = 21)

Mean	Intervention
3.81	- Provide honest responses to questions asked by siblings.
3.71	- Encourage parents to spend time with their other children.
	- Encourage siblings to ask questions.
3.67	- Reassure siblings they will not catch illness.
3.52	- Reassure siblings they did not cause illness.
	- Encourage parents to bring siblings to hospital.
3.48	- Encourage expression of feelings by siblings.
	- Acknowledge positive behaviors of siblings.
3.45	- Encourage a balance in family life so focus is not continually on ill child.
3.38	- Provide parents with anticipatory guidance for potential areas of difficulty with siblings.

Table 24

Practice Responsibility and Mean Value for Intervention Use

	Staff Nurse n =41	Clinical Nurse Specialist n =51	Pediatric Nurse Practictioner n =21
Nursing careplan	2.75	3.04	2.90
Family conference	2.33	2.29	2.29
Subsequent conferences	2.39	2.51	2.67
Visit hospital	3.61	3.82	3.65
Orient to unit	3.23	3.08	2.74
Educate about disease	3.20	2.92	3.00
Participation in care	3.15	3.20	2.95
Update on progress	2.56	2.94	2.81
Provide advanced information	2.98	2.88	2.90
Prepare for changes	2.68	2.86	3.00
Identify support network	2.83	2.82	2.81
Facilitate supportive relationships	2.90	3.14	3.10
Encourage expression of feelings	3.34	3.47	3.48
Encourage questions	3.56	3.65	3.71
Provide honest responses	3.68	3.78	3.81
Acknowledge positive behaviors	3.44	3.33	3.48
Parent/sibling bereavement group	3.20	3.31	3.14
Nurse/sibling bereavement group	2.88	3.15	3.05
Parental anticipatory guidance	3.34	3.57	3.38
Encourage time with other children	3.80	3.76	3.71
Parental assistance	3.24	3.33	3.00
Educate community agencies	2.18	2.69	2.45
Changes in family system	2.93	3.26	3.10
Family balance	3.46	3.57	3.45
Discuss death	2.33	2.59	2.60
Illness cause	3.56	3.65	3.52
Catch illness	3.59	3.73	3.67
Parents discuss death	3.23	3.43	3.33
Reference materials	2.66	2.84	2.86
Research findings	2.12	2.57	2.65

Simple Regression Analyses

The analyses to determine the possible effect of the variables of educational degree, years of pediatric nursing experience, and practice responsibility on Sibling Social Support Questionnaire responses included a series of simple regression tests. The regression of the Sibling Social Support Questionnaire responses on educational degree (F value = 1.485, significance of F = .2253), years of pediatric nursing experience (F value = 3.174, significance of F = .0772), and practice responsibility (F value = 1.073, significance of F = .3820) was not statistically significant at the .05 level.

Chapter 5

Discussion

The purpose of the current study was to investigate what interventions pediatric oncology nurses utilize in their current practice to provide social support to siblings of children with cancer. It was also designed to determine which interventions to provide social support, are utilized more frequently, and to determine if the interventions vary with educational degree, years of pediatric nursing experience, and practice responsibility. This study had a particular emphasis on the social support variables as suggested by House (1981).

Frequently Used Interventions

As previously reported in Chapter 4, the ten most commonly utilized nursing interventions in clinical practice by pediatric oncology nurses include:

(1) Encourage parents to spend time with other children;

(2) Provide honest responses to questions asked by siblings;

(3) Encourage parents to bring siblings to hospital;

(4) Reassure siblings they will not catch the illness;

(5) Encourage siblings to ask questions;

(6) Reassure siblings they did not cause the illness;

(7) Encourage a balance in family life so that the
focus is not continually on the ill child;

(8) Encourage expression of feelings by siblings;

(9) Provide parents with anticipatory guidance for
potential areas of difficulty with siblings and

(10) Acknowledge positive behaviors of siblings.

Comparisons between results of the current study and
that of Walker et al. (Table 25) show similar findings.
The ten most frequently cited sibling facilitative
behaviors rated as being most important in the Walker
study included:

(1) Open communication;

(2) Make siblings feel special - e.g., spending more
time with them;

(3) Encourage consistent discipline for all children;

(4) Encourage open visitation to hospital and clinic;

(5) Provide attention - recognize and interact with
siblings;

(6) Advocate sibling needs to family;

(7) Provide anticipatory guidance - e.g., discuss
troublesome issues such as guilt over causing
illness, fear that it is contagious;

(8) Provide education on disease;

(9) Provide empathy for sibling needs, feelings and

(10) Build self-esteem - identify what siblings can do
to help.

A more critical analysis of all interventions, and
their rankings (Tables 7 and 25) demonstrates many
similarities in interventions used in meeting the
psychosocial needs of siblings of children with cancer.

Table 25

Sibling Facilitative Behaviors

Mean	Rank	Behavior
4.69	1.	Open communication - answer questions honestly
4.65	2.	Make them feel special too, e.g., sibling day, spending time with them, special sibling activities
4.45	2.	Encourage consistent discipline for all children
4.39	3.	Open visitation to hospital and clinic
4.33	4.	Provide attention - recognize and interact with them
4.27	5.	Advocate sibling needs to family
4.27	5.	Anticipatory guidance - deliberately bring up issues that are known to be troublesome such as guilt over causing it, or fear that it is contagious
4.24	6.	Education on disease and treatment - developmentally appropriate
4.24	6.	Empathy for sibling needs, feelings
4.18	7.	Build self-esteem - identify what they can do to help

Table 25 (cont.)

4.08	8.	Provide information on sibling needs & concerns
4.00	9.	Encourage telephone calls
3.94	10.	Reassure them as much as possible
3.92	11.	Sibling support group
3.86	12.	Positive accepting attitude - cheerfulness
3.82	13.	Facilitate support services for siblings - e.g., peers, transportation, child care
3.76	14.	Involve siblings in patient's care
3.72	15.	Humor
3.59	16.	Play/art therapy - therapeutic play, medical play
3.57	17.	Continuity of staff working with family
3.55	18.	Orient to hospital/clinic - provide tours
3.55	18.	Facilitate school intervention for siblings
3.53	19.	Touch
3.49	20.	Include siblings in family and/or treatment decisions

Note. From "A Delphi Study of Pediatric Oncology Nurses' Facilitative Behaviors" by C. Walker et al., 1992, Unpublished Study, p. 20.

The most frequently used interventions by pediatric oncology nurses in this study were directed at providing emotional and informational support. These findings are consistent with data reported by Williams (1992). As previously outlined in chapter two, Williams found that health care providers described emotional or affective support as the first component of providing social support. The second component of the professionals' definition of support was offering education or informational support. It is clear from the results of this study that nurses in clinical practice do indeed place a great deal of attention on these two areas of social support. An interesting aspect of the study by Williams (1992) was that parents rarely identified teaching or information as an important component of support. They mentioned the need for instrumental support before informational support. On the other hand, professionals identified instrumental support as the third component of support. These findings emphasize the importance of assessing what the perceived needs are of the individual members of the family. Similarly, the need for support as perceived by the sibling(s) should also be addressed.

The findings suggest that pediatric oncology nurses utilize in practice the nursing interventions considered

by pediatric oncology clinical experts to be the most important in the care of siblings of children with cancer. It is important to note that these are interventions that <u>nurses</u> believe to be most important. An extensive review of the literature failed to reveal any literature in the area of perception of support from the perspective of the sibling. As previously cited, health care professionals, when compared with parents, differ in their ratings of the importance of different types of support. This may also be the case with siblings as well. In any case, it is important that nursing interventions to provide social support to siblings of children with cancer continue to be used to meet the psychosocial needs of siblings.

Another area of concern stems from reasons for decreased use of specific interventions or of many interventions by nurses. In analyzing comments from the comments section of the Sibling Social Support Questionnaire, some factors impeding nursing provision of support were noted. One nurse who reported having used interventions infrequently, qualified her responses by stating: "Many times I would like to do more with siblings but because of heavy patient loads, with a lot of technical tasks, I find that caring for siblings is often left to do later." Another nurse commented: "I

don't feel it is my place to do a lot of teaching and counseling with siblings, especially when it is busy." These findings are consistent with those found by Williams (1992). Lack of nursing staff and time, intense workloads and obstacles posed by family members were identified as being the major factors impeding staff provisions of support. On a more positive note, several nurses identified the need to support siblings. One nurse was very reflective of her feelings: "I think siblings often suffer more than the ill child. Siblings need to be given information as well as ongoing emotional and verbal feedback to help maintain some sense of normalcy within their lives." Other nurses identified that if they were too busy to meet siblings' needs, they sought out the help of child life specialists, recreation therapists or child psychologists. One nurse summed things up nicely when she stated "when a child is diagnosed with cancer I believe you do not get just a new patient, but a family, including siblings."

Themes pertaining to the importance of using social support interventions with siblings permeated the comments. It is not a question of whether these interventions are important or not, but of who will provide them and when. It is also important to try to

determine who in the health care setting is best able to
provide each of the interventions aimed at helping
siblings to adjust to the childhood cancer experience.
As described in Chapter 4, pediatric oncology nurses,
regardless of their educational level, years of
experience, or practice responsibility, all tend to
utilize the same nursing interventions with close to the
same level of frequency. It would be beneficial to
determine who on the nursing care team is best prepared
academically, most experienced, or in the most
advantageous role to carry out the many interventions
aimed at providing social support. One example of the
importance of assigning certain interventions by
practice responsibility can be represented by the
following comment made by a nurse participating in the
study: "As a Clinical Nurse Specialist, I do not have
enough contact with siblings to carry out many of the
interventions you have identified. I often provide
guidance for the staff nurses on the unit to empower
them to deal with sibling issues. Other times they look
to me to help families, such as in educating about the
disease or helping to find support groups."

The following recommendations for practice may prove
helpful, not only to the nurses working in the pediatric

oncology setting, but in all areas of pediatrics where siblings are present.

Recommendations

Implications for Practice

Although the diagnosis of childhood cancer has a major impact on the entire family system, it seems to have an even greater impact on siblings. Nurses working with children with cancer have not only the opportunity but also the responsibility to see that "comprehensive" family centered care is also aimed at meeting the siblings' psychosocial needs. The literature clearly shows that to date, the psychosocial needs of siblings have been underemphasized in the comprehensive care of the child with cancer. One of the most difficult and challenging tasks facing today's pediatric nurse is how to avoid causing psychosocial maladaptation in siblings of children with cancer during the efforts to achieve control over the disease process.

As more is learned about the effects of the childhood cancer experience on the family system, pediatric practitioners are gaining an increased awareness that just as with children with cancer, a comprehensive approach to sibling intervention is needed as well. Pediatric nurses working with children with cancer are in primary positions to help prevent sibling

maladaptation from becoming an inevitable consequence of childhood cancer.

Pediatric nurses may use a variety of strategies that can be instrumental in facilitating sibling psychosocial adaptation. However, before any strategies are implemented, it would be highly beneficial to complete a thorough family assessment. This assessment should include knowledge of the number and ages of siblings, how much they know about the ill children's illness, how much the parents want the siblings to know, the nature of the sibling relationship (i.e., birth order, child spacing within families, previous relationships), what type of social support resources are available for siblings, what crises the family has faced in the past and how they coped with them. It is important for practitioners to consider these questions in order to address the most imminent needs.

Early interventions with siblings should result in inclusion in initial and subsequent family conferences throughout the childhood cancer experience. Siblings should be considered when formulating the plan of care for the ill child and their progress and needs assessed periodically. Involving siblings in this process is beneficial for two very important reasons: (1) it provides the nurse with direct access to the sibling

where an accurate assessment of psychosocial adaptation can be completed and (2) it allows well siblings to offer information and a different perspective on the situation that may have been overlooked by others. Because of this unique perspective, siblings may have much to offer to the clinical management of the ill child.

Siblings should be encouraged to visit the ill child in the hospital. Not only does this foster a sense of participation in their ill sibling's care, but it also encourages the maintenance of the relationship between children. This also becomes another opportunity for practitioners to assess the adjustment of the sibling to the illness experience. Siblings should also be oriented to the hospital environment to gain a sense of mastery over what happens during the ill child's hospitalization. A supportive relationship between siblings and hospital staff should be facilitated as well. Nurses should ensure that siblings are provided with accurate, age-appropriate information about the disease, its treatment, side effects, and prognosis if necessary. It should be emphasized that the well sibling did not cause the disease and that they will not catch it. It is important that siblings also be updated with age-appropriate disease-related information as

changes in the ill child's condition occur. Siblings should be encouraged to express feelings. They need an opportunity to share the feelings and emotions that develop as a result of the childhood cancer experience. It is important that they know that even though their parents spend more time with the ill child, they are still loved and cared about despite what is happening in their family during the painful experience of childhood cancer. Siblings should be encouraged to ask questions and provided with honest answers. When providing any information to siblings, the parents should be consulted initially and their wishes as to what is to be explained to their well children respected.

Anticipatory guidance should also be provided for parents to help ameliorate potential areas of difficulties and sources of stress for siblings. Parents should be encouraged to explain the changes in the family system as a result of the illness experience. Well siblings need to understand that the changes in roles and responsibilities are temporary and will return to normal when the ill child is well. It should also be advocated that they spend time with their other children. Because many parents have difficulty reconciling the demands of the healthy children versus the ill child, assistance should be provided to parents

to facilitate their ability to meet the psychosocial needs of all their children.

Finally, an assessment of the existence and use of support systems should be an integral part of providing comprehensive family centered care to the family with a child with cancer. Community agencies (i.e., schools, churches, social groups) should be educated about their potential role in helping to meet the social and emotional needs of siblings.

Recommendations for Education

A critical component for providing comprehensive family-centered care is understanding the psychosocial needs of the healthy siblings in addition to the ill child and their parent(s). Caring for children with cancer calls not only for a need for special knowledge and sensitivity of the ill child's needs but those of the healthy siblings as well. Greater attention should be placed on sibling responses to childhood illness in the pediatric programs of nursing curriculums. Students enrolled in nursing, and other health related programs of study, should have course content directed toward addressing the needs of healthy siblings confronted with illness experiences of childhood. Academic programs should emphasize that, just as with the child with cancer, a comprehensive approach to sibling intervention

is necessary and requires the psychosocial assessment of non-disease as well as disease-related stressors. The ability of nurses in academia to utilize a vast number of resources, to provide lectures and continuing education programs, and where possible, practical clinical experiences, should be taxed to the fullest to enable students, and all health care professionals, to better understand what is involved in this very complex patient care experience.

Pediatric oncology nursing is one of the most complex and emotionally difficult challenges in nursing. Nursing educators have a great responsibility in educating nursing students and nursing staff in clinical practice in ways to provide sensitive, holistic care to the entire family.

Recommendations for Future Research

The literature clearly demonstrates that the childhood cancer experience is a stressor that may increase subjective feelings of stress by well siblings and in some cases lead to decreased psychosocial competencies and increased psychopathologies. Walker (1992) cites that research on siblings with cancer has made some progress over the past few years. Research has expanded from identifying psychosocial problems after the patient's death to identifying stressors

during the illness experience. More recent studies have
been targeted at identifying what siblings do to cope
with the stressors imposed since the diagnosis of
childhood cancer.

Although some research on the psychosocial
adjustment of siblings of children with cancer has
focused on the possible positive outcomes of the illness
experience, most have taken on a deficit-perspective
approach. Research on the role of the sibling
relationships in mediating the stressors of the illness
experience and enhancing sibling psychosocial adaptation
should be studied further. Sibling relationships are
powerful subsystems that can be used to promote positive
adaptation. Rollins (1990) points out that the
bidirectionality of the sibling relationship should be
considered when exploring the benefits of interventions
with siblings. The potential exists for siblings to be
a source of strength and comfort for each other.

Research on sibling adaptation to the childhood
cancer experience has also underemphasized the role of
social support as a mediator of illness-related effects
on siblings' psychosocial adaptation. Types of social
support that are relevant to sibling adjustment include
emotional support, informational support, instrumental
support and appraisal support. Correlational research

would be instrumental in determining the possible relationships between specific nursing interventions aimed at providing different types of support and both short-term and long-term adaptive and maladaptive outcomes. Furthermore, experimental studies would also be valuable to test the effectiveness of these nursing interventions at reducing maladaptive outcomes and enhancing coping with an adaptive outcome. Finally, research aimed at identifying what interventions siblings perceive as supportive would also be of immense value. Understanding the effects of the childhood cancer experience on siblings, and nursing interventions aimed at moderating them, involves a complex matrix of variables that will only be fully comprehended with further research in the area of sibling adaptation.

Conclusions/Summary

The results of this study demonstrate that pediatric oncology nurses are cognizant of the need to provide social support interventions to meet the psychosocial needs of siblings of children with cancer. This research has provided some support for the study of facilitative behaviors conducted by Walker et al. (1992).

There are some issues specific to the current study which affect the interpretability of the results. One

is that the interpretation of the current findings is somewhat limited by the small sample size and variations in subjects according to educational degree, practice responsibility, years of experience, etc. A larger, more diverse sample would most likely demonstrate clearer relationships between the variables of educational level, practice responsibility, and years of experience on the number and types of interventions used in clinical practice.

Another issue is the validity and reliability of the Sibling Social Support Questionnaire. The fact that the measure relies solely on self report complicates the question of its adequacy when one considers the possibility of the social desirability response factor. Hopefully, further analysis and use of this measure will lead to methodological and conceptual improvements over time.

The findings of this study suggests that effective interventions with siblings of children with cancer should be included in the family-centered approach to care. However, it is important to note that implementation of nursing interventions to provide social support to siblings should not be utilized on the basis of solitary studies. Rather, interventions should be evaluated and implemented based on findings

which have been replicated clearly in the research literature.

Research should include not only what nurses think are important sibling interventions, but also what siblings perceive as being helpful interventions. We should continue to investigate variables such as educational degree, practice responsibilities in the health care setting, and years of clinical experience and their relationship to the number and types of interventions used. This should help to increase our understanding of and ability to reduce the incidence of maladaptive outcomes and enhance sibling adjustment to pediatric cancer with an adaptive outcome.

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APPENDIX A

Cover Letter

26 Holly Lane #3D
Chestnut Hill, MA 02167

Dear APON Member,

I am a graduate student in the Pediatric Acute and Chronic Care Nursing Program at Boston College, Chestnut Hill, Massachusetts. For my thesis, I am conducting a study to examine the ways in which Pediatric Oncology Nurses utilize specific nursing interventions to help _siblings_ of children with cancer better cope with a potentially traumatic experience. The limited research done over the past 30 years has identified many maladaptive outcomes in children who have a sibling with cancer. Included in these studies were recommendations of interventions that may be helpful in reducing the incidence of such outcomes. The purpose of this study is to learn more about the use of these interventions in clinical practice.

Your name was selected at random from the Association of Pediatric Oncology Nurses. I hope you will help in this study by completing the enclosed demographic information sheet and questionnaire. Your responses are very important and greatly needed to assess how we are meeting the needs of siblings. Responses to the questionnaire are **anonymous,** therefore you can feel confident about giving your honest responses. This study will provide insight into how pediatric oncology nurses can better meet the needs of siblings of children with cancer.

Please take a few minutes to complete and return the enclosed study. It should take no longer than 15 minutes. Enclosed is a self-addressed, postage-paid return envelope provided for your convenience. To assist me in analyzing the responses in a timely manner, please return the questionnaire to me by February 1,1993. Your returned response will constitute informed consent. If you have any questions, please feel free to call me collect at (617) 277-3528. My research advisor, Dr. Victoria Mock, can also be contacted at (617)552-8821.

Thank you very much for giving so freely of your valuable time so that others can benefit from your responses.

Sincerely yours,

John S. Murray, RN, BSN

APPENDIX B

Demographic Information Sheet

DEMOGRAPHIC INFORMATION SHEET

AGE _____   SEX _____

DO YOU HAVE CHILDREN ? _____   IF YES, HOW MANY ? _____

HIGHEST EDUCATIONAL DEGREE RECEIVED

    Diploma _____   Masters _____

    AD _____   Doctorate _____

    BSN _____   Non Nursing College Degree _____
                    (Please Specify Type) _____

PRACTICE SETTING

    INPATIENT MEDICAL CENTER   _____
    INPATIENT COMMUNITY HOSPITAL SETTING   _____
    INPATIENT BONE MARROW TRANSPLANT UNIT   _____
    COMBINATION ONCOLOGY/ BMT UNIT   _____
    COMBINATION ONCOLOGY/ PEDIATRIC UNIT   _____
    OUTPATIENT CLINIC SETTING   _____
    OTHER (WRITE IN)   _____

FUNCTIONAL AREA

    PATIENT CARE   _____
    EDUCATION   _____
    RESEARCH   _____
    ADMINISTRATION   _____
    OTHER (WRITE IN)   _____

POSITION

    STAFF NURSE _____   HEAD NURSE _____
    CNS _____   PNP _____
    EDUCATOR _____   RESEARCHER _____
    SUPERVISOR _____   ADMINISTRATOR _____
    OTHER (WRITE IN) _____

SIZE OF UNIT

    0-10 BEDS _____   21-30 BEDS _____
    11-20 BEDS _____   > 30 BEDS _____

APPROXIMATELY HOW MANY HOURS A WEEK DO YOU SPEND PERFORMING DIRECT PATIENT CARE ? _____

HOW MANY YEARS OF NURSING EXPERIENCE DO YOU HAVE IN CARING FOR PEDIATRIC ONCOLOGY PATIENTS ? _____

HOW MANY YEARS OF EXPERIENCE DO YOU HAVE IN PEDIATRIC NURSING? _____

APPENDIX C

Sibling Social Support Questionnaire

SIBLING SOCIAL SUPPORT QUESTIONNAIRE

PART I

DIRECTIONS : In answering the items below, please consider your usual clinical practice and circle the number that best describes the extent to which **you include the following interventions in your current practice.** Assume that the interventions are age specific and developmentally appropriate.
Please use the following scale:

	Never	Sometimes	Often	Always
	1	2	3	4

1. I consider siblings when I formulate the nursing care plan   1   2   3   4

2. I encourage the inclusion of siblings in the initial family
conference at the time of diagnosis   1   2   3   4

3. I include siblings in subsequent conferences   1   2   3   4

4. I encourage parents to bring siblings to the hospital   1   2   3   4

5. I orient siblings to the pediatric/pediatric oncology unit   1   2   3   4

6. I educate siblings about the disease based on developmental
level   1   2   3   4

7. I encourage participation of the sibling in the ill child's care   1   2   3   4

8. I update siblings on the ill child's progress   1   2   3   4

9. I provide more advanced information to siblings as their
developmental level increases   1   2   3   4

10. I prepare siblings for changes that may occur   1   2   3   4

11. I identify formal and/or informal support networks for
siblings (i.e. peer support groups)   1   2   3   4

12. I facilitate a supportive relationship between siblings
and hospital staff   1   2   3   4

13. I encourage expression of feelings by siblings   1   2   3   4

14. I encourage siblings to ask questions　　　　　　　1　2　3　4

15. I provide honest responses to questions asked by siblings　　1　2　3　4

16. I acknowledge positive behaviors of siblings (i.e. achievements
　　　in school, sports etc.)　　　　　　　　　　　1　2　3　4

17. I encourage parents to include siblings in bereavement groups　1　2　3　4

18. I encourage siblings to attend bereavement groups　　1　2　3　4

19. I provide parents with anticipatory guidance for potential
　　　areas of difficulty with siblings　　　　　　　　1　2　3　4

20. I encourage parents to spend time with their other children　1　2　3　4

21. I provide assistance to parents to facilitate their ability to
　　　meet the psychosocial needs of their other children　　1　2　3　4

22. I educate community agencies (i.e. schools, churches) about
　　　their potential role in helping to meet the social and emotional
　　　needs of siblings　　　　　　　　　　　　　1　2　3　4

23. I encourage parents to explain changes in the family system
　　　to their well children (i.e. changes in roles and responsibilities)　1　2　3　4

24. I encourage a balance in family life so that the focus is not
　　　continually on the ill child　　　　　　　　　　1　2　3　4

25. I discuss the concept of death with siblings　　　　1　2　3　4

26. I reassure siblings they did not cause the illness　　1　2　3　4

27. I reassure siblings they will not "catch" the illness　　1　2　3　4

28. I encourage parents to discuss death with siblings　　1　2　3　4

29. I provide siblings with reference materials　　　　1　2　3　4

30. I counsel parents about research findings pertaining to
　　　responses of siblings　　　　　　　　　　　1　2　3　4

(Please continue on the next page)

PART II

COMMENTS. It can be very frustrating to circle responses to items without being able to explain your answers in more detail. I'm very interested in any comments you may have about this topic or questionnaire. Please use this section to identify interventions that you may use in clinical practice to help siblings or to let me know how you feel about the topic. **Please remember that all responses are anonymous**. **THANK YOU** once again for your time and very important responses.

APPENDIX D

Reminder/Follow Up Letter

26 Holly Lane #3D
Chestnut Hill, MA 02167

Dear APON Member,

Several weeks ago I wrote to you about a study I am conducting to look at nursing interventions used in clinical practice to reduce the maladaptive outcomes of siblings of children with cancer. Thank you to those who have returned questionnaires. For those who have not, it would be most helpful if you would return your completed materials to me within the next two weeks if you are interested in participating in the study. If you have any questions about the study, please feel comfortable in calling me collect at (617) 277-3528. The success of this study depends on your participation and I want to do whatever I can to make it easier for you to respond.

Thank you for participating in my study. I sincerely appreciate your willingness to help others gain from your experience.

Sincerely yours,

John S. Murray, RN, BSN